Psychological perspective on the quality of life of women with lipoedema

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Our questions

• What are the factors that affect quality of life in women with lipoedema?
• What are those psychological factors that we can impact to improve the quality of life of those with lipoedema?
Participants’ Age

Study 1 N=118

Study 2 N=328 M=49.18; SD=11.24
BMI (Body Mass Index)

**Study 1**
M=41.24; SD=15.24 N=113

**Study 2**
M=42.51; SD=14.94 N=321
Lipoedema affects quality of life in all domains

- Physical health
- Psychological
- Social
- Environmental
Quality of life in women with lipoedema and in general population (WHOQOL-BREF, Transformed scores)

Livskvalitet hos kvinnor med lipödem och befolkningen i allmänhet

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health domain</td>
<td>73.5</td>
</tr>
<tr>
<td>Psychological domain</td>
<td>70.6</td>
</tr>
<tr>
<td>Social relationships domain</td>
<td>71.5</td>
</tr>
<tr>
<td>Environmental domain</td>
<td>75.1</td>
</tr>
</tbody>
</table>

- Women with lipoedema
- General population
Little knowledge among health professionals and in general population
Weight stigma, anti-fat bias
Environmental barriers

Pain
Associated medical conditions

Mobility
Appearance-related distress

Depression
Anxiety
Disordered eating

Psychological flexibility
Social connection

QUALITY OF LIFE

Lipedema is little known
Weight stigma is prevalent

Women with lipedema encounter various environmental barriers
Lipoedema Symptom Severity

Pain
SYMPTOM SEVERITY (STUDY 2)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>No</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extremely Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swelling</td>
<td>5.5</td>
<td>23.2</td>
<td>25.3</td>
<td>29.3</td>
<td>16.8</td>
</tr>
<tr>
<td>Muscle Pain</td>
<td>11.9</td>
<td>22.3</td>
<td>24.1</td>
<td>27.1</td>
<td>14.6</td>
</tr>
<tr>
<td>Joints Pain</td>
<td>10.7</td>
<td>16.5</td>
<td>27.7</td>
<td>27.7</td>
<td>17.4</td>
</tr>
<tr>
<td>Fat Tissue Pain</td>
<td>7.3</td>
<td>14.0</td>
<td>34.8</td>
<td>26.8</td>
<td>17.1</td>
</tr>
</tbody>
</table>
Chronic pain from psychological perspective

• „Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (International Association for the Study of Pain, 1994)

• Importance of psychological factors
  • Gate Control Theory, proposes a neural ‘gate’ that can be opened or closed in varying degrees to modulate incoming pain signals before they reach the brain (Melzack, Wall, 1965)

Psychological factors that may affect pain perception

Increased pain perception
- Anxiety, worry, tension, depression
- Pain avoidance
- Boredom (little involvement in daily activities)
- Loneliness

Lower pain perception
- Gratitude, joy, fulfillment, excitement
- Pain acceptance
- Involvement and interest in important life activities
- Companionship
How to cope with pain in lipoedema?

- Multidiciplinary approach - most effective

- Monitor your (your patient’s) pain and various factors that may affect it: What is affecting your pain? When is it more severe? When is it less severe?
Associated medical conditions
Associerade medicinska tillstånd(%)

- Fibromyalgia/Fibromyalgi
- Hypermobility/Hypermobilitet
- Hypothyroidism/Hypotyreo
- Irritable Bowel Syndrome/Irritabelttarmsvold
- Venous Insufficiency/Venös insufficiens
- Arthritis/Artit

0 10 20 30 40 50 60 70
Associated medical conditions need further and more detailed investigation. They all may contribute to lower quality of life. Treatment needs to be individualized.
Mobility

person’s ability to perform everyday tasks: any of usual work, housework or school activities, usual hobbies, recreational or sporting activities
Maximal Function of Lower Extremities (LEFS) (Study 2)

<table>
<thead>
<tr>
<th>% of women</th>
<th>0-25%</th>
<th>26-50%</th>
<th>51-75%</th>
<th>76-100%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>26.2</td>
<td>30.8</td>
<td>27.4</td>
<td>15.5</td>
</tr>
</tbody>
</table>

Mobility

• Lowered perception of pain
• Lower risk of depression
• Lower likelihood of weight gain
• Lower risk for cardiovascular and respiratory disease
• Better overall health, and specifically brain health
Mobility from psychological perspective

What are your barriers to be more physically active?
What are your patients barriers to be more physically active?
Appearance related distress

negative emotions of fear, social anxiety, shame, and negative affect along with a behavioral response of avoidance and withdrawal that frequently disrupts lifestyle.
http://doi.org/10.1348/135910705X27613
Weight stigma is prevalent.

Weight stigma affects health

- Psychological disorders
- Lower physical activity
- Binge eating
- Increased calorie intake
- Physiological stress
- Weight gain

“Evidence collectively demonstrates negative implications of stigmatization for weight-related health correlates and behaviors”

When do you experience appearance-related distress?
When is your patient experiencing appearance-related distress?
What would you do differently if you were proud of the way you look like?

How the appearance related distress is stopping your patient?
Help yourself/ your patient to cope with appearance-related distress and do what matters now!
Appreciate the Beauty of Your Body

Alive Breathing Changing

Sculpture „Paris Pekin“ by Marie Madeleine Gautier
http://www.mmgautier.fr
Celebrate body diversity
Advocate for body diversity

How to get a bikini body?

Put a bikini on your body.

#EachBodysReady
Eating disorders

- Overly restrictive dieting
- Excessive focus on the appearance, food, weight
- Binge-eating episodes
- Purging after meals (compensatory behaviors)
- Shame related with eating
- Self-evaluation based on shape/weight
EDE-Q (mean score) in women with lipoedema and in women in general population

EDE-Q (medelvärde) hos kvinnor med lipoedem och hos kvinnor i allmän befolkning (Study 1)

Self-reported eating disorders
Självrapporterad ätstörningar (Study2)

- 31.5% of women who reported having an eating disorder
- 68.5% of women who haven't reported having an eating disorder
Why women with lipoedema may be at risk of developing eating disorders?
WHAT WOULD BE YOUR WAY OF EATING?

• What would support the way YOU want to live?
• What suits your HEALTH, has good LONGTERM consequences?
• What allows you to ENJOY your life?
• It is your MINDFUL CHOICE
• Process of choosing
Be aware of moments of choice
Choose wisely
Surf the wave of discomfort
And enjoy!
Anxiety and depression
Why women with lipoedema are at risk for depression?

- Difficulty in controlling the disease
- Restrictive dieting, malnutrition
- Pain
- Lack of physical activity, immobility
- Loneliness
- Experiences of fat shaming, weight stigmatization
- Neuroinflammation

Visious circles of depression

- Depression → Lower physical activity → Depression
- Depression → Weight gain → Depression
- Depression → Loss of positive reinforcement (e.g. social interactions, success etc.) → Staying indoors → Depression
- Depression → Pain → Depression
Psychological aspects of functioning in women with lipoedema need to be included in multidisciplinary approach to treatment.
Individual factors

ACT and connect to live better with lipoedema
ACT (Be psychologically flexible) (psykologisk flexibilitet)

Accept → Choose → Take action
Psychological flexibility mediates the change in various health related problems

- chronic pain,
- fibromyalgia,
- stigmatization,
- depression,
- anxiety,
- weight management,
- body dissatisfaction,
- physical activity,
- disordered eating

Psychological flexibility was related to:

- Better quality of life,
- Lower level of depression and anxiety
- Lower level of appearance related distress
- Higher level of mobility and lower symptom severity
Focus on what you can control and accept what is beyond your control

Live meaningful life now, don’t postpone your life for later

When you move towards what matters, you may encounter pain or discomfort

Engage in important activities even in the presence of pain or discomfort

If needed re-formulate your goals

Take care of your own health as you would take care about your loved one

Be psychologically flexible (ACT)
CONNECT (Social Connection)

Balance Reciprocity

1. Being vulnerable → Acceptance
2. Self-disclosing → Understanding
3. Asking for what you need → Giving

Increase in odds of mortality due to various public health conditions

Loneliness has serious consequences to our longevity, health and well being

Hostility and wound healing

- Step 1: Lab “conflict interaction”
- Classified as “high conflict” or “low conflict”
- Step 2: Each participant given “suction blister” wound
- Step 3: Measure number of days for full healing of wounds

Kiecolt-Glaser; Loving; Stowell; Malarkey; Lemeshow; Dickinson; Glaser

<table>
<thead>
<tr>
<th>Number of Days for Full Healing to Occur (and this one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8</td>
</tr>
</tbody>
</table>

**Conclusion:**
Good relationships may promote faster healing and physical health.
Social connection was related to:

- Better quality of life,
- Lower level of depression
- Lower level of appearance related distress
- Lower symptoms severity
Maintain relationships with people that you can rely on
Speak your truth
Listen empathetically
Take perspectives
Express your needs
Respond the needs of the other
Try it at the conference: ask someone and share

• For what in your life do you feel most grateful?
• If you could change anything about the way you were raised, what would it be?
• What is your biggest dream?
• What do you value most in a friendship?
• What is your most treasured memory?
• If you knew that in one year you would die suddenly, would you change anything about the way you are now living? How?
Conclusions for health professionals

Symptom severity (pain!), mobility, appearance-related distress, psychological functioning (depression, eating disorders) are important factors affecting quality of life in women with lipoedema.

Psychological functioning should be assessed and patients at risk should get support that they need.
Conclusions for families and friends

- Try to listen to and understand your loved one
- Don’t minimize her experience
- Ask what kind of support she needs
- Be a role model of body appreciation
- Advocate for patients with lipoedema and body diversity
Conclusions for patients

- ACT and Connect
- Follow your dreams
- Find your own voice
- Find social support
- Maintain healthy relationships
- Take care of yourself
- Take one step at a time
- Dream big!
- Change the world one person at a time
Thank you!

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